Relatives' strategies in subacute brain injury rehabilitation

The warrior, the observer and the hesitant

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DECLARATION OF INTEREST

The authors have no conflict of interest to declare.

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Abstract:

Background: Relative involvement is crucial in rehabilitation when patients are incapable of being involved due to cognitive and functional dysfunction. However studies have shown that this is complex because of differing understandings of the meaning of involvement as well as diverse needs to be involved.

Aims and objective: We explored the experience of the rehabilitation process from the perspectives of relatives of patients with a traumatic brain injury. The aim of the study was, through a theoretical-empirical analysis, to identify relatives' strategies and practices in the rehabilitation process as evidenced in meetings with providers.

Design: A longitudinal study with a qualitative approach, drawing on the theory of Pierre Bourdieu. **Methods:** Data were generated using participant observation and semi-structured interviews. Participants were eleven relatives of patients with a severe traumatic brain injury, followed through in-patient rehabilitation varying from nine to twelve weeks. Analysis was undertaken using both an inductive and deductive approach.

Findings: Drawing on Bourdieu's concept of strategy, three relative positions were identified, the warrior, the observer and the hesitant. These positions illustrate how different relative positions and their related dispositions influence the strategies used by relatives of patients with a severe traumatic brain injury evidenced in how they act, participate and relate to both the patient and the providers during the course of rehabilitation.

Conclusions: Acknowledging the relatives' positions during the rehabilitation process enables better understanding and support of the relatives in the rehabilitation process in order to meet their (and thus the patients') diverse needs.

Relevance to clinical practice: The findings have practice implications in informing how clinicians meet, interact, communicate, and involve relatives of adult patients' with traumatic brain injury in decision-making during rehabilitation.

Keywords: Bourdieu, Decision-making, Interdisciplinary team, Qualitative research, Rehabilitation, Relatives, Traumatic Brain Injury.

INTRODUCTION AND BACKGROUND

Traumatic brain injury (TBI) is a major health concern throughout the world (Roozenbeek et al., 2013; Maas et al., 2008; Sundstrøm et al., 2005) causing death and disability (World Health Organization, 2009). Patients with a severe TBI are admitted to an intensive care unit and, if they survive, often have severe physical impairments and disabilities as well as

behavioral, social and cognitive sequelae, which require long-term rehabilitation (Benedictus et al., 2010). These impairments affect the patient's participation in the decision-making process during the admission to a rehabilitation department and relatives become important participants as a proxy to advocate for patients (Doser & Norup, 2016). In Denmark, as in other countries shared decision making is integral to a patient centered care approach and there is political emphasis on increasing involvement of patients as well as relatives (Ministeriet for Sundhed og Forebyggelse (The Ministry of Health), 2014; Videnscenter for Brugerinddragelse i Sundhedsvæsenet (The Danish Knowledge Center for User Involvement in Health Care), 2014, 2015). Research has found that relatives' involvement is linked to better rehabilitation outcomes for individuals with a TBI (Foster et al., 2012).

Relative participation in rehabilitation could be understood as involvement of the relatives as a resource in the patient's course of disease which is particularly important if the patient is not conscious, as in many patients with a TBI. It could also be understood as actively involving patients and relatives in goal-setting: Defining their wishes, making an action plan to achieve their goal, and making decisions about their own care (Leach et al., 2010; Holliday et al., 2007). However, there are challenges in the way patients, relatives and healthcare providers (hereafter called providers) grasp what involvement means and the implications of being involved. While specialized in-patient rehabilitation providers are used to working with patients with severe TBI, families are not. They do not have formal training and support to care for persons with severe TBI (Ramkumar & Elliott, 2010). The new situation can be very stressful and overwhelming. Little knowledge, however, exists about the experiences of families and individuals with TBI in the rehabilitation process. A Swedish study conducted by Jumisko et al. (2007) themed 'being excluded', highlighted how patients and relatives felt avoided by staff, and had a sense of being ruled by authority (Jumisko et al., 2007). Their experiences of exclusion also included patients' and relatives´ unmet

informational and emotional needs. A range of studies support the evidence that relative and patients have unmet informational and emotional needs during the inpatient rehabilitation process (Keenan & Joseph, 2010; Bond et al., 2003; Mirr, 1991; Lefebvre & Levert, 2012). Bond et al's study highlights how relatives need to make sense of the traumatic experience, and how they take on a caregiving role, wanting to be involved in the care in the initial stage of rehabilitation (Bond et al., 2003). Problems being involved are expressed by relatives as a feeling of being 'in the way' of the health care professionals (Bond et al., 2003). From another perspective, a Norwegian study examining caregiver burden and quality of life found that 30% of family members of patients with severe TBI reported an increased caregiver burden, one and two year post-injury (Manskow et al., 2017). Knowing that increased caregiver burden might have a negative impact on the person with severe TBI, Manskow et.al (2017) suggested that more tailored follow-up of patients and family members is needed with a focus on professional support to relieve burden (Manskow et al., 2017).

While previous studies show that relatives of patients with TBI are important participants during the patients' rehabilitation process, relatives express different needs for information and support, as well as different opportunities and wishes of being involved in the rehabilitation process. It is therefore important for both practice and research to explore how to differentiate relatives and their different ways of interacting in neurorehabilitation and especially how this can be tied to their earlier experiences, resource and competences. Such knowledge can be used to identify the range and diversity in needs for involvement, information and support.

Theoretical approach

To examine the experiences of relatives in rehabilitation, we focused on their beliefs and practices, their capacity to mobilise resources, as well as how they were able to situate themselves in the processes of field of rehabilitation specifically and the healthcare system

generally. Bourdieu's conceptual triad of habitus, capital and field enable consideration of relatives' prior assumptions, beliefs and experiences (habitus), the material or symbolic resources that can be leveraged in encounters in healthcare (capital), and the context of rehabilitation itself (the field), all of which will shape their capacity to achieve the outcomes that they desire (Collyer et al., 2015). Bourdieu's related concept of disposition is used to analyse different relatives' diverse capital volume and composition of capitals and how this influences their decision-making in the rehabilitation process, because these predispose, but do not predetermine how individuals act in everyday life. The concept of positions enables exploration of how these dispositions perform in the field of rehabilitation. Bourdieu's theories are applied worldwide in different fields and the extra value of the theories are the epistemological breaks with everyday constructions often associated with e.g. psychological, individualistic, cognitivist or moral concepts (Bourdieu et al., 1991). Thus, social and bodily practice are located and understood not only as interaction in organizations, but as different practices in different social fields (e.g., like persons are acting in a bank, at a festival or in a medical field). Thus, analytically Bourdieu's concepts help to provide insight into differently positioned relatives' strategies. Lastly Bourdieu's theory adds to other theories on how relations of dominance work on both micro, meso and macrolevel, e.g. how differently positioned relatives are more or less confident in the field depending on different amount and compositions of capital.

To our knowledge, no earlier studies map different positions and dispositions relatives of individuals with a severe TBI possess. We assume that it is possible to map some classifications, because patients and relatives behave differently based on demographic information like social class, gender, age, the ability to cope and eventually also by factors such as the aetiology of the trauma etc. (Bourdieu & Bennett, 2010). If it is possible to identify different positions and dispositions possessed by relatives of individuals with a

severe TBI, it would be possible to differentiate their needs for support and information from the health care providers. This would potentially benefit both patients and relatives.

The aim of this study was to undertake theoretical-empirical analysis of relatives' strategies and practices in the rehabilitation process as evident in meetings with providers. We explored the experience of the rehabilitation process from the perspectives of relatives of patients with a TBI. Our research question was 'what kind of strategies do relatives of patients with a TBI apply and use in the rehabilitation process?'.

METHODS

As outlined above, key concepts from Bourdieu's conceptual triad of capital, field and habitus and the concept of strategy guided the study's research questions, methodological choices, the construction of the interview guide, and techniques to work with the empirical data (Bourdieu & Bennett, 2010; Bourdieu & Accardo, 1999).

Design

We designed a longitudinal study comprising participant observations of interdisciplinary meetings (meetings) followed by qualitative semi-structured interviews.

Setting

The study was conducted in a sub-acute 22 bed highly specialised rehabilitation department for patients with severe TBI at a university hospital in Denmark from November 2016 to September 2017. The department is one of two centralized departments in Denmark.
The observations were undertaken during the meetings which are considered as key elements of empirical focus because this is where decision-making regarding rehabilitation takes place. The purpose of the meetings was to discuss the clinical assessment of the patient and the patient's likely prognosis, length of stay and later in the rehabilitation process, also the discharge destination. In the meetings attended the patients´ relatives, the members of the patient's interdisciplinary team; nurse, neurological consultant, physiotherapist, occupational therapist, neuropsychologist and speech-lingual pathologists when relevant. The first meeting

was on the day of the patient's admission at the clinic and the relatives were informed at the neuro intensive unit that a meeting would take place and that their participation was expected. The meetings were followed up every three weeks until discharge.

Participants

The participants were eleven relatives of nine patients with severe TBI with impaired consciousness at admission to sub-acute rehabilitation in the states of unresponsive wakefulness syndrome (UWS), minimally conscious state (MCS) or posttraumatic confusional state (Laureys et al., 2010; Katz et al., 2009). Therefore patients were not cognitively able to participate, neither in the interdisciplinary status and planning meeting (hereafter called meeting) nor in being interviewed. There was a majority of male patients, probably because they are in a high-risk group of being involved in motor vehicle accidents, violence and work related accidents (Roozenbeek et al., 2013; Maas et al., 2008) (Table 1). Participating relatives were recruited in collaboration with the interdisciplinary management group of the rehabilitation department using purposeful sampling (Polit & Beck, 2014) to achieve a broad variation of participants in terms of social position in education, profession, and financial circumstances. We included relatives from the working class, positioned in low positioned jobs (e.g. a cleaner), relatives from middle class positions (e.g. a bank employee), and relatives in high positions (e.g. executive positions). The participants had varying age and relationship with the patient (Table 1). Participating relatives were 18 years or older and able to read and understand Danish. Patients were also 18 years or older.

Data Collection

Observations

Moderate participation observations as defined by Spradley (1980) were undertaken by the first author, meaning that the researcher was identifiable to the participants, (particularly becoming more familiar to them over time as multiple meetings per patient were attended) but did not actively participate in the meetings. The first author was present in the clinic approximately 30 minutes before and after the meetings, doing observation of the relative's interactions. A theory based observation recording schedule was constructed, focusing on the interactions between relatives and the providers with particular attention to how the participants were involved. Field notes were taken during and after the meetings. Twenty-two meetings were observed. The meetings were scheduled for 30 minutes and lasted between 20 and 46 minutes.

Interviews

In order to capture the participants´ habitual dispositions and their experiences of the rehabilitation process, in-depth individual interviews with eleven relatives immediately after, or within three days of meeting by the first author. A semi-structured interview guide was constructed, based on Bourdieu's concepts, to explore patients' and relatives' experience of the interaction with the providers, experience with their own involvement and information as well as decision-making during in-hospital rehabilitation. The interview guide consisted of two parts. Part one was used at the initial meeting and the questions were related to the patients' and relatives' upbringing and educational background, past experience with illness and the health care system, habitual dispositions on exercise, eating, alcohol, medicine and smoking, economic background and social network. Part two was used at the following meetings and at discharge and the questions focused on the rehabilitation process, examining patient and relatives' experience of the interaction with the providers and experience with

involvement and information. As an example one relative was asked: 'I noticed that you are writing a lot of things in your notebook during the meeting. Do you mind telling me what you are noting down and why?' Examples of the topics from the semi-structured interview guide have been provided in table 2.

The number of interviews with each relative varied from two to three depending on the length of the admission. Interviews (n=23, lasting 23-140 min) were recorded digitally and transcribed verbatim. In one case both parents of a patient participated together in the interviews, supplementing and supporting each other (relative ID 7). In another case a parent couple both wanted to participate in the study, but were interviewed separately as they did not wish to be interviewed together (relative ID 9a+b).

Analysis of observations and interviews

Analysis of interviews and field notes was undertaken using both an inductive and deductive approach using a computer assisted analysis: QSR International NVivo version 10. In the following, the process of analysis is described as if it was a linear process, but the analysis was a back and forth movement between the two approaches.

Inductive Phase of the analysis

A qualitative content analysis was undertaken of both observations and interviews (Graneheim & Lundman, 2004). This analytical approach aims to identify and accept multiple meanings, focusing on the manifest content in the data. The analysis followed the procedure suggested by Graneheim and Lundman (2004). First, the transcribed interviews and field notes were read though several times to get an idea of the visible, obvious components in the text. Second, important word, sentences and/or repeated contents were marked and noted and meaningful units of the texts were identified, which enabled identification of the visible, obvious component or manifest content in the data. Third,

meaningful units in the text, were abstracted into four categories: Bodily and verbal interaction, Relation with the providers, Perception of own involvement and Perception of the patient's illness (Graneheim & Lundman, 2004).

Deductive phase of the analysis

In the deductive phase of the analysis, the concept of strategy, disposition and position was applied to the empirical data to provide a relational and a dynamic approach to the analysis, as well as enabling us to construct the different positions of the relatives and their strategies. The Bourdieusian concept of disposition was used to analyse relatives' diverse capital volume and composition of capitals and how this influenced their decision-making in the rehabilitation process. The concept of positions was used to explore how these dispositions performed in the field of rehabilitation. It formed some underlying/fundamental assumptions about the participants embodied experiences (dispositions and habitus). The constructed types are a theoretical construction, where the characteristic which is assumed to be substantial in order to map the different relatives thinking, acting and life course was selected. The identified categories were entered into a descriptive matrix (Averill, 2002; Miles et al., 2014) to facilitate the examination of how relatives´ diverse strategies intersected with each category. An example, from the category 'relatives relation to the patients illness' has been provided in table 3. According to Miles & Huberman (1994), a descriptive matrix in qualitative analysis, involves 'the crossing of two or more main dimensions . . . to see how they interact' (Miles et al., 2014, p. 239).

Ethics

This study received approval from the Danish Data Protection Agency (ID 04346), and data were handled according to its requirements, and registered with the Danish National Committee on Health Research Ethics (ID 17000765). The study was conducted according to

the principles of the Declaration of Helsinki. Written and verbal information was given before obtaining informed consent to participate in the study. Participants were informed of the voluntary nature of the study and that withdrawal from the study was possible at any time with no implications for future treatment or rehabilitation. Pseudonymns are used when reporting findings.

FINDINGS

Three different positions among the relatives in rehabilitation were evident: the warrior, the observant and the hesitant. The warriors are characterised as being proactive and fully engaged in decisions about care, and directing the processes to maximize the benefit for their relative. The observers are collaborative with, and helpful to, providers and are concerned to do whatever providers direct as being in the best interests of their relative. The hesitants are characterized as being primarily reactive to the decision making processes and uncertain of their role.

While these relative positions are presented as if relatives occupy only one position this is not the case in practice. The relatives fluctuate between the positions depending on both the patient's condition and progression, and their growing expertise with the rehabilitation field. However, the initial interactions with the providers, habitus and capital influence the roles that are played and their related dispositions influence various strategies used. These initial positions are evident in how relatives act, participate and relate to both the patient and the providers during the course of rehabilitation, just as the relatives ability to adjust to the field-specific rules that are internalized in the rehabilitation institution ('the rules of the game'). It seems that the cultural preferences are differently distributed among these different positions and this influences the strategies able to be adopted. For example, it became evident in the initial interviews that the warrior tends to occupy more privileged positions in society, based on education, cultural capital (e.g. holds relatively high

to medium high economic capital) and cultural preferences for example distinctive preferences in terms of food, beverages, shopping malls. The observer tends to occupy moderately privileged positions in society (e.g. self-employed work or permanent employment in small private enterprise) and cultural preferences for example distinctive preferences in movies, literature and theater. The hesitant, on the other hand, seems to occupy moderate to less privileged positions in society (e.g. unskilled work) and cultural preferences go towards, for example, distinctive preferences in reading, television series and food.

The three positions were constructed by centering on the following four categories that emerged from the data: Bodily and verbal interaction, Relation with the providers, Perception of own involvement and Perception of the patient's illness.

Bodily and verbal interaction

In the category termed bodily and verbal interaction relatives presented themselves differently in the meetings both bodily and verbally, which was evident in their capacity to use cultural and social capital as a strategy in the rehabilitation process.

During the meetings the warrior bodily appearance is prepared, sitting in the front of the chair often with the arms resting on the table, often with a paper and pen. The warrior mostly has good eye contact with the professional and exhibits non-verbal communication (e.g. leaning back in the chair and folding arms across one's chest if they do not agree with the providers). The warrior is present in the department most of the day and evening hours, so the meeting is part of their engagement in the department. The warrior attends the meetings with one or more other members of the close family.

During the meetings the warrior was keen to share their own observations about the patient, for example, relative ID 5 indicated the importance of this at interview:

> 'I was absolutely sure that behind the filter, he was present. And there was none of the staff seeing it. So that part I felt was totally frustrating and I felt like I should fight for his rights. I think I should fight and tell them what I was observing looking through the filter that they did not see' (relative ID 5).

This indicates that the warrior are aware that their observations is important for the further rehabilitation process and that they find that health professionals do not always observe the same progress that they do. The warrior asks many questions of the providers during the meetings indicative of confidence from middle or higher education (medium to high cultural capital) and therefore the capacity to leverage their cultural capital into dialogue with the providers.

Similar to the warrior, the observer appears prepared during the meetings and asks clarifying questions of the providers. During the meetings the observer is interested in the providers' professional view on practical issues such as: numbers of visitors, visiting hours and coordinating visitors, as well as more existential questions as rehabilitation outcome, length of stay and economic issues. During the meetings, the observer primarily is concerned with practical conditions such as duration of hospitalization, visit times and coordination of these visits.

Contrary to the warrior and to a lesser extent the observer, both of whom appear familiar with the meetings, the hesitant wears outdoor clothes, suggestive of a visitor in the room. The hesitant is seated back in the chair with arms crossed and does not seek eye contact with the providers. The hesitant often leaves the department immediately afterwards the meetings. The hesitant is engaged in the meetings to hear the providers provide information about the patient's progress, primarily with regard to physical functions. They also express concern

about the future: ‘I think about when he gets better and if he will ever become normal and what we will do in the future’ (relative ID 4).

Relationship with the providers

The relatives’ relationship with the providers during the course of rehabilitation varied across the three positions, both in the expectations of who should provide information, as well as the way they were able to communicate and cooperate with and relate to the providers. This appeared to be related to the relatives’ different levels of capital, particularly cultural capital, which shaped the relatives´ ability to effectively navigate the rehabilitation process and the interactions with the providers. Cultural capital was important in shaping the different experiences of the relationship with the providers.

The warrior´s relationship to the providers is, to a great extent, based on dialogue. Warriors perceive a great need to receive information from the providers, especially from the physician who was viewed as the most reliable source of information. The warrior prefers daily contact with the physicians, particularly in the beginning of the admission. The warrior critically refers to who gives information. The following example illustrates this point:

> ‘It is very important that you do not get different information, diverse information. And from whom you get information from. It is not inconsequential from whom you get it. It should not be the lowest-ranking nurse. You need to be informed by the responsible, competent doctor or nurse’ (relative ID 9b).

The warrior requires extra meetings with the consultant and is able to achieve this multiple times during the hospitalization, even when such meetings are outside the standardized rehabilitation process.

The warrior is aware that they interfere with the established order and/or balance of power, but is also aware of the boundaries of their behavior. For example, relative ID 7 said: 'You must behave properly, that is, if you are not empathetic or people do not like you, then you can act as badly as you possibly do, you're just tripping yourself' (relative ID 7). The warrior can appear demanding, critical and/or challenging: 'Sometimes I've known a bit better, I really have' (relative ID 3). They often consider themselves to be the expert to judge the quality of care and treatment. In contrast to the hesitant and the observer, the warrior has capacity to leverage their cultural capital in their interactions with providers. While they may not master the specific biomedical language, classifications and logic, they can convert cultural capital to acquire the dominant language, attitudes and preferences. 'I have some strategies that I use in my daily professional life which I can also use in this room' (relative ID 7).

The observer considers the providers as collaborative partners, where the observer cooperates with the providers for the benefit of the patient. The observer wishes for greater access to information, like a weekly meeting rather than the monthly progress meeting, but does not voice this need. Thus, the observer´s relation to the providers is characterized by solidarity and loyalty. The observer will voice concerns, but will wait until staff are available, rather than demand immediate resolution. This is indicated by relative ID2 who states: 'Although I know that there is a lot of staff, there are also many patients and there are many that are complex, so we do not always see anyone. But then, if we have a question, we will wait until someone (provider) appears' (relative ID 2).

The hesitants' relation to the providers is on the other hand characterized by one-way communication and humility to the expertise, trusting that the providers are well equipped to manage the patient's care. It is the providers who are considered experts in the

field of rehabilitation, and the observer does not ask question or raise critical issues about treatment and decision making. While the hesitant may express the need for more information; they are uncertain of actions to obtain it and therefore seems to be a passive recipient of information. The hesitant does not acquaint themselves with the specific course of the disease, and puts trust and faith in the rehabilitation team's treatment choices. 'I don´t ask a lot of questions. I just don´t' (relative ID 1). In other words the hesitant relates and responds passively to the health professionals. Because the hesitant has generally low to moderate economic and cultural capital, they primarily perform with the hands and not verbally or intellectually, and thus have less capacity to engage in dialogue with the providers. The hesitant 'melts into the wallpaper' when visiting and asks none or only very few questions of the providers. The hesitant considers they are a visitor to the rehabilitation unit and neither receives or gets care tasks nor undertakes care and/or treatment tasks from the providers.

Perception of own involvement

The three relative positions had differing perceptions of their own involvement, in terms of how to act and participate in the rehabilitation process. This can partially be attributed to their opportunities to deploy cultural capital and economic capital, for example having flexibility from the place of employment is of great importance in enabling attendance at the progress meetings.

The warrior draws on their own role and activity, such as attorneys, lawyer, guardian, extended arm, coordinator and instrument, and considers themselves as partners with the providers in the decision making processes. The warrior acts as a quasi-professional and is present during the entire hospitalization process. Warriors have the capacity to spend many hours every day in the department indicative of a work situation with maximum

flexibility to enable such a response. ‘I have been there day and night. I think I've been there between 12 and 18 hours, every day for 80 days’ (relative ID 3).

The warrior is involved with care, thus developing a whole range of specialist skills and knowledge during the rehabilitation process e.g. being legitimized to administer medication. Furthermore the warrior is able to appropriate and apply field specific languages and rules. For example, they learn how to cooperate with the nurses in a way that displays competence but does not overstep nurses’ professional qualifications. For example, a relative (father) explained how he over time had built up confidences with the nurses, so he was allowed to deactivate the equipment that measured the oxygen level in the blood, without consulting them (relative ID 7).

The warrior is active and dynamic and does not always agree with the professionals’ assessments and decision making. To some extent, the warrior is able to adjust ‘the rules of the game’, questioning the rules by taking action, potentially accessing more benefits and services from the providers. As an example a cohabiting male was dissatisfied with a decision made by a nurse concerning a drainage tube: ‘Then I simply went out and found the doctor. I knew all the neurosurgeons and most of the nurses and all anesthetists and everybody in fact. So I went in and got it all started’ (relative ID 3).At the same time the warrior considers himself as an ideal relative, particularly where he can supply resources that are articulated by the professionals as needed. ‘You're almost working as a therapist, it's really cool’ (relative ID 3).

In contrast to the warrior, the observer must adjust to ‘the rules of the game’. This occurs by observing and assessing, not questioning the information the providers give during the progress meetings as well as the providers’ actions during their daily visits to the department. ‘I observe a lot but I know that he is in good hands’ (relative ID 8). Observers only take action if necessary but behave otherwise neutrally. The observer experiences their

own role as being in a challenging balance between other roles and responsibilities. For example, the observer experience being in a conflict balancing family life, work and visiting the patient at the hospital. This has the consequence that the observer constantly feel guilty about not being able to be enough either at home, at work or at the hospital, and is indicative of less flexibility from the workplace and in their other roles.

A different perception of 'own involvement' is demonstrated by the hesitant, who possesses a wait-and-see attitude. The hesitant is a layperson that does not pay attention to themselves and appears silent, avoiding conflict and having faith in authority to a certain limit. 'We take one day at a time' (relative ID 1). But there are also examples showing that if the hesitant experiences his/herself as unfairly treated, this becomes explicit to the providers. As an example one sister explained how she felt in an interaction with a physician, frustration over not getting a promised meeting: 'We felt so bad. As if it was the family they had been pushing for a meeting, it was actually initiated by another doctor. It feels like one hand does not know what the other hand is doing' (relative ID 1). She explained how she expressed her dissatisfaction at not getting the meeting. In this way it appears that the hesitant is able to talk back to the providers, if they feel their boundaries are crossed, but is not part of their usual disposition to give words to their frustration to others positioned above themselves.

The hesitant experience minimal flexibility from their workplace, which means that the hesitant needs to prioritize their work, rather than being at the hospital. As a consequence, the hesitant visits the hospital for 1-2 hours a day, 2-3 times a week, and calls in daily for the patient's condition. Visits are most often in the evenings, where there are not so many providers present. The hesitant, rarely asks for the providers help since they does not want to inconvenience the providers. 'I feel like it's only if I really need help I will to ask for it' (relative ID 8).

Perception of the patients' illness

Relatives' positions also differed concerning perceptions of the patients' illness and interpretation and ascription of value regarding potential disabilities.

For the warrior the mental and cognitive aspects of the illness were most important, and indicative of valuing the cognitive capacities above others. 'It does not matter if there is increased function of the arms and legs as long his intellect is preserved' (relative ID 5). The warrior participates actively in training and ward rounds where they are part of a professional back-and-forth interaction with the providers. The warrior's strategy is to obtain the most achievable, lengthy and most effective rehabilitation, as possible. 'If that is the best place, then we have to bring him there, even if it was on the moon' (relative ID 7).

Similar to the warrior, the observer highlights the mental and cognitive capacities, and only has little concern about the physical disability that might remain after the rehabilitation process. 'I am not afraid to get Peter home in a wheelchair. Handling a wheelchair will not be a problem for me. As long as Peter can use his arms, his mental functions and his language, so we are able to communicate' (relative ID 8). The observer participates in training and during ward round if they happen to be present in the department rather than participation being an active choice.

In contrast to the warrior and the observer, the hesitant is concerned about the physical disability, rather than the mental and cognitive disability, which means that they are more inclined towards the functional and physical body. 'Well, it does not matter if you forget things once in a while. That's the least. As long as he does not have pain and will be able to walk again' (relative ID 6). The hesitant does not participate, or rarely participates, during the training sessions or during ward rounds and therefore appears to be passive regarding involvement in care and treatment. The hesitant's stance towards rehabilitation is

that rehabilitation should take place as close to home as possible, although it is not necessarily the best facility, according to the providers professional assessment.

DISCUSSION

The main finding of our study was the identification of three different relatives' positions in sub-acute neurorehabilitation determined by the individual's habitual dispositions, which provides a set of underlying dispositions indicating how the relatives are able to navigate through the rehabilitation process.

By analyzing how relatives bodily and verbally interact, how they relate to the providers, how they perceive own involvement and how they perceive the patients' illness the generative themes and strategies of the relatives (e.g. perception, thinking, feeling, evaluating, speaking and acting) become evident. This is, for example, reflected in the warrior who develops knowledge and skills during the rehabilitation process, (e.g. engaging in medical preparations and administering medicine) as well as acquiring 'rehabilitation language' and the field-specific rules. The Bourdieusian concept 'hexis' (bodily element) enables us to reconstruct a mode of practices, as part of one's habitus, that will appear (expressive, verbal and practical) in different empirical areas. So for example an individual who possesses language-using practices, being proactive, active and inquiring will have a tendency to always act the same way in similar situations and will often bear the same features (bodies, apparel, posture), in the bank (economic field), in the private life, in the bringing up of children as well as in health care field. When the types of habitual dispositions are acquired is it possible for the language user to improvise and produce linguistic expressions that are not only grammatically correct but also suitable for particular situations. It can be expressed as a capacity to produce appropriate terms 'apropos' i.e. convenient and timely (Bourdieu 1991, p. 7). But it could also involve a capacity to be heard, believed, and

trusted and perhaps even obeyed particularly if there is a reception from the dominating actors within the specific field (Bourdieu & Wacquant, 1992**)**.

The relative positions we have identified are theoretical constructs that are not directly applicable to label concrete persons or social groups. The positions in rehabilitation are not meant to categorise relatives as being 'good relatives' or 'bad relatives', 'difficult relatives' or 'easy relatives'. In addition the relative positions are not meant to be used only in a descriptive and functional manner. It needs to be understood in a dynamic sense and fundamentally as a framework to think with. According to the sociologist Max Weber (1968) an ideal type is formed from characteristics and elements of the given phenomenon, but it is not meant to correspond to all of the characteristics of any one particular case (Weber, 1968). Thus, every relative will have minor or major fragments of the characteristics of the three positions, but the positions should cover possible discrepancies in the observed field of practices. Thus, these ideal types are not meant to correspond to all of the of any one particular case. Relatives' positions enable us to think, prepare and try to understand the relative's diverse way of acting in-patient rehabilitation and not a normative category. It is an attempt to extend the 'types' of relatives beyond patients stereotyped by providers.

A key finding was that the warrior, observer and hesitant showed diverse needs for information and support during the rehabilitation process. If the providers are aware of the differences between relatives they could provide are more equal treatment and care in the rehabilitation process. Providers should be able to accommodate different individuals, and in order to do this, providers must treat relatives from their point of view and not the providers' point of view. The need to individualize information and support for patient' and relatives' parallels previous research. For example Lefebvre and Levert (2012) examined the needs of people close to individuals with a TBI, from the point of view of the individuals with a TBI and providers. Similar to our study, Lefebvre and Levert fund that whatever information

relatives do receive must correspond to their individual needs here and now, both in terms of content and quantity and preferable coming from few sources (Lefebvre & Levert, 2012). Sekse (2012) identified three typologies in a qualitative study, describing how the women, in different ways, negotiate living through cancer illness (Sekse et al., 2012). In line with this current study Sekse et.al (2012) concluded that there in cancer care is a need to create a follow-up process that is individually tailored for each patient.

Another finding was the different relatives' positions diverse need of being involved in the rehabilitation process. As our findings suggest, patients and relatives have different starting points (dispositions and habitus) and thus different possibilities and needs for being involved in the rehabilitation process are expressed. It is therefore important to consider relatives habitual dispositions, in order to determine the relatives' influences and desires about being involved as well as their decision-making capacity, when involving them in the decision-making process.

It is evidenced in the literature that active involvement of relatives is a key element in successful rehabilitation, yet very complex. As suggested by Fisher et.al. (2017) relatives should be acknowledged and utilized in the decision making process and relatives and providers should work collaboratively together to maximize rehabilitation outcomes (Fisher et al., 2017). This is in line with findings by Kuipers (2014) stating that relatives must be engaged more effectively in the rehabilitation process (Kuipers et al., 2014). However, it would appear of great importance to include relatives' habitual dispositions, as their habitual dispositions determine different forces to be involved as well as decision-making capacity, when being involved in the decision-making process. While a recent study has focused on how to increase family involvement by developing a theoretical model to increase family

involvement for individuals with brain injury (Fisher et al., 2017), other studies have examined the barriers of involving patients and relatives. From the perspective of the providers Levack (2009) illustrated how barriers of involving family members in goal-setting were perceived as related to the family' unrealistic objectives for rehabilitation and timeframe for recovery and was thought not always to be in the best interests of the patient (Levack et al., 2009). In a study conducted by Asimakopoulou et. al. barriers in involving patients, were linked to difficulties with overly engaged patients (asked to many questions, came with so much questions, came with too much information, were to demanding and took up to much time) or less keen patients not interested in joining in with decision-making (Asimakopoulou et al., 2014). What these studies miss are to take into account the meaning of the individuals' habitual dispositions and the different strategies they apply as a consequence of that. If the providers do not know the relatives starting point, it seems difficult to individualize and tailor the specific need for involvement of the relatives, which suggest that the interdisciplinary team of providers should be offered information and education about the different relative positions strategies, in order to match the relatives' different need for being involved.

Strengths and limitations

Complementing observations with semi-structured individual interviews enables the gathering of perspective that might otherwise be missing in rehabilitation, particularly because the voice of an individual with a severe TBI may be hard to hear otherwise. The use of Bourdieus´conceptual framework enables deepening of our understanding of the strategies applied by relatives in a nuanced way and it is seems apparent that if this framework is productive in relation to this, it is likely to be of relevance also to a wider range of other long-term conditions afflicting patients and relatives. The methodological rigour of this study rests on the fulfilment of four quality criteria of Lincoln & Guba (1985). First, credibility (internal validity) was ensured by methods triangulation using different data collection methods and by

researcher triangulation continuously reflecting upon the interview process and analysis to ensure that the analysis reflected the data. Second, transferability (external validity) was ensured by providing contextual information, so it is possible appraise whether the findings are applicable to other contexts, situations, times and populations. Third dependability was ensured by describing in details the research design, data collection and analysis. Finally, confirmability was established by a constant reflexive account throughout the entire research process about the researcher's position and role.

During data analysis findings were presented to managers and clinicians (managers of nursing, doctors, physiotherapy, neuropsychology and occupational therapy) at the rehabilitation department, enabling their involvement in reflecting about how to make use of the different relatives' positions in these goal-setting meetings. This was relevant, because of reorganization of the interdisciplinary goal-setting meeting in the unit aiming to involve all relatives more. Previously relatives were not part of the interdisciplinary goal- setting meetings, but due to a greater organizational focus on relatives' involvement, acknowledging the importance of meeting the relatives' diverse needs to get involved in the rehabilitation, the management group had prioritized this change. The triangulation of involving the managers and clinicians as co-investigators somehow validated the clinical usefulness of the findings. As an example they thought that it would be useful to use it to educate the staff, before attending meetings with relatives. It also gave the opportunity to discuss how the finding could be used in practice by the provider's in order to actually meet the relative's diverse need and to get the relatives more involved in the rehabilitation process, if that is the need. In addition a stronger focus on the providers' capability of meeting the different positioned relatives were discussed.

This study only focused on relative's practice and position in the field of rehabilitation, with no focus on the position of providers or on the interactions in other places than before and after the meeting and in the meeting room. It appears reasonable to assume that it is the specific field that defines what appears and articulates different layers of one's habitus. Habitus is a series of dispositions that can be adapted to time and place, which is not captured in this study, as relatives were not observed in different places or at different time points of the day other than in relation to the meeting. In spite of the fact that we did not directly examine how the relatives acted outside of the medical field, we assume that there is a tendency toward a sense that relatives of patients with severe traumatic brain injury think, speak and perform in the medical field and to the position they hold in the social space, outside the medical field.

CONCLUSION

By identifying three different relative positions in neurorehabilitation, this study contributes a new framework for understanding how providers should meet and support relatives in rehabilitation differently in order to meet their (and thus the patients') diverse needs. Our findings highlight the importance of providers being able to differentiate relatives need for information, support and involvement. This new knowledge about different relative positions and their diverse needs for information, support and involvement is an important contribution to the clinicians working in the field of rehabilitation, because it offers a way of thinking that can assist clinicians to reflect about their own practice.

RELEVANCE TO CLINICAL PRACTICE

At an organizational level we recommend that findings from this study result in reviewing existing policies and guidelines and, where needed, develop new policies and clinical guidelines promoting and integrating relatives diverse need for information, support and involvement.

Bourdieu's relevance in clinical practice derives from his focus on the body, materiality and practice theory. Here the inter-relational perspective demonstrates how broader social space, fields and interactions are inter-related and further the theory invites for reflections on relations between the researcher and the object (Bourdieu 1992). In similar way knowledge from these studies are convertible to and can have educational implications informing nursing practitioners about patients and relatives and different strategies.

On a clinical level we stress the importance of providers receiving additional education, so they are able to integrate knowledge about different relative's position, be able to identify the different types of relatives, and adjust the information to the needs of each patient and relative. In this way, relatives might feel involved, listened to and that will potentially could increase their satisfaction with treatment and care and thus able to communicate more effectively preventing misunderstandings.

Furthermore, findings from this study may assist further research in patient and relative involvement.

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IMPACT STATEMENT

What does this paper contribute to the wider global clinical community?

- This paper contributes to insight about the importance of integrating knowledge of different relatives positions in the planning of rehabilitation in order to meet the relatives' (and thus patients) diverse needs
- It provides insight into how relatives' diverse strategies need to be acknowledged by the healthcare professionals in order to provide the optimal information, emotional and practical support
- Identification of relatives' positions enables clinicians to interact, communicate, and involve relatives to adult patients' with traumatic brain injury in the decision-making in the rehabilitation process

Table 1. Characteristics of the patients and relatives

Patient ID	Gender	Age	Relation	Relatives	Relatives occupied
1	Male	52	Siblings	Sister	Yes
2	Male	29	Mother-son	Mother	Yes
3	Female	39	Cohabiting	Cohabiting male	Yes
4	Male	38	Married	Wife	No
5	Male	26	Married	Wife	Yes
6	Male	72	Daughter-Father	Daughter	Yes
7	Male	18	Parents	Mother and father	Yes
8	Male	59	Cohabiting	Cohabiting Female	Yes
9a	Male	31	Mother-son	Mother	Yes
9b	Male	31	Father-son	Father	Yes

Table 2. Topics from the semi-structured interview guide

Part one (first interview with the relative)
Upbringing
Educational background
Economic background
Social networks
Past experience with illness and the healthcare system
Part two (follow-up interviews with the relative)
Current status of the disease and rehabilitation process
Relationship and interaction with the providers
Relatives experience of participation and involvement in the decision-making process

Table 3. Example from the matrix analysis, in the category 'relatives' relation to the patients illness'

The warrior	The observer	The hesitant
• The mental and cognitive body is important for *the warrior.* The mental and cognitive dysfunction associated with a TBI was a dominant concern to the relatives, which means that they are cultural inclined." • Participates actively in training and during ward rounds where they are part of a professional back-and-forth with the providers	• The observer participates in training and during ward round if they happen to be present in the department and participation is therefore not an active option.	• Concerned about the physical disability, rather than the mental and cognitive disability, which means that they are more inclined towards the functional and physical body. • Does not participate or rarely participate during the training sessions or during ward rounds and therefore appears to be passive for involvement in care and treatment.